Chapter 2

Low-Technology Aids for Daily Living and Do-It-Yourself Devices

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> There is no greater increase in function than from nothing to something.
>
> *Peter Leech*

Everyday technology is often taken for granted, even by advocates with disabilities, but tools for daily living are frequently needed *before* the rest of the technology can be beneficial. Usually more mundane than glamorous, everyday technology rarely involves high-technology or computer applications. If it is working right, and working as a system, it can and should fade into the background.

Technological support for everyday living is all pervasive. It is also intrinsically related to adaptive strategies and personal assistance services. Without some combination of these three supportive services, a person with a disability may not be able to get out of the house, into bed, eat dinner, take a bath, or put on clothes. The combination of supportive services used is very individualized and changes over time and circumstance.

In many ways, everyday technology is the most challenging of all technological interventions. It can be highly personal and can involve body functions in very private ways. It has the least amount of funding available, however, because it does not easily fit into most medical, vocational, or educational categories. Furthermore, because it is by definition home- and community-based, it does not fit well into the traditional service delivery categories. The basic principles that guide wise choice and use of everyday technology need to be tightly woven into all the aspects of technological support systems, high-technology and specialized products included. Unfortunately, these principles are sometimes in direct conflict with reimbursement requirements; for example, Medicare's regulatory demand that the device not be useful to a healthy or unin-

jured person makes it difficult to buy an off-the-shelf product at a discount store and adapt it for a person with a disability. People with disabilities must learn to differentiate between the medical model problem-solving rationale that drives third-party reimbursement and a more practical approach that will work for them—whether or not third-party payment is available. Professionals should help people with disabilities learn pragmatic principles for choosing and using tools for living, especially since they must pay for most everyday technology.

BENEFICIARIES: EVERYONE

The usefulness of everyday technology is not limited to any particular group of people. Everyone uses it, and poor design appears to be a universal problem (Norman, 1988; Papanek, 1983; Papanek & Hennessey, 1977). Improvement in design to make a product intrinsically more accessible to people with disabilities promises to improve the product for everyone.

Everyone whose life is touched by a person with a disability sooner or later comes into contact with that person's tools for living. Equipment selection should take into account the everyday contacts, such as caregivers, assistants, classmates, and co-workers. If the device works for the individual with a disability, but detracts from the life of co-workers, or is potentially dangerous to a caregiver or personal assistant, something went amiss in the original selection process. The same is true if the device is effective, but has an aura of stigma and creates interpersonal barriers for the people who use it. This is the assistive technology equivalent of "the operation was a success, but the patient died."

Everyday technology that works, generally works for everyone. Those with disabilities who find or invent practical technology to help them in the activities of daily living (ADL) are not usually surrounded by appliance-like equipment; they have aesthetically pleasing, helpful gadgets that do not look out of place, even when they are performing a task for which they were not designed. When they work, they are clever—so clever that a person without a disability may find them useful.

DEVELOPMENT OF TOOLS FOR DAILY LIVING

Left to Your Own Devices

Many gadgets in the professional catalogs and literature are focused on the daily living needs of people with disabilities. The most successful items, as well as the best methods for evaluating, selecting, and using appropriate devices, are developed primarily through self-help, however, based on trial and error rather

than professional intervention. Thus, leaving people with disabilities "to their own devices" is not necessarily a bad thing. The more control these people have over their technology, the better. It is detrimental for professionals to try to assume control of an individual's tools for living, because their control creates an undesirable dependency and reduces the individual's motivation to become a designer, an inventor, and a problem solver.

Even so, people with disabilities should not just be abandoned to their own wiles in the jungle of daily living. There is a significant role for professionals in daily living technology. The transitions from the role of patient, the role of consumer, and then to the role of inventor are important in the career of a person with a disability. The professional may begin as a teacher, evolve as a coach, and ideally become a partner, even a student, as the person with a disability develops strategies that can be shared with peers and professionals.

From the perspective of the person with a disability, the locus of control moves from the external to the internal. The capacity for change and growth becomes self-directed. Therefore, the process of acquiring the device can be very important. The person's development of a self-help orientation for everyday technology can have a profound impact, providing a tangible mechanism through which that person can regain control of his or her life in everyday activities and decision making. Professionals need to foster problem-solving skills. If the individual does not understand how the professional developed the solution, the individual will not be able to develop strategies in the future. Reinvention is a successful strategy and outcome if performed by a person with a disability. The difference between giving someone a fish and teaching someone to fish is particularly applicable in the realm of tools for daily living.

An individual's need for experience and practice with the devices that may become a part of his or her ongoing support system is frequently overlooked. A survey of occupational therapists indicated that less time was spent on training in independent living skills than may be necessary or desirable (Pendelton, 1990). Occupational therapy consumers have described training in home- and community-based skills as the most deficient, least addressed form of intervention during their rehabilitation stay (Rogers, 1979). Professional rehabilitation intervention is often not available after hospital-based rehabilitation is finished, usually because of the lack of funding. In rural areas, the distance from a source of professional services may be an additional complication.

Consumers and their families should learn about the benefits and availability of professional services, as well as the best way to seek these services when needed. They also need to understand the value of being self-reliant and taking charge of their own ongoing "rehabilitation." For example, in order to optimize function, they need to know how to select mass market products for desirable characteristics and where to get updated, reliable information in the future. Ide-

ally, the teaching of these consumer skills would be part of the initial hospital-based rehabilitation process; but instruction in community-based independent living skills is not usually a component of the inpatient rehabilitation experience. There are notable exceptions, such as the independent living skills training programs designed for older people who are losing their vision that focus almost exclusively on skills needed for integration into the community. These programs rarely use a medical model, focus on person–environment interactions, and highlight consumer-identified ongoing community-based needs.

Disability As a Difference in Degree

The do-it-yourself (DIY) approach to tools for daily living is as old as humankind. In fact, one of the characteristics that distinguishes the human animal from the other apes is the human's ability to develop and elaborate on tools. It is most likely that we survived as a species because we were clever enough to develop tools that make up for our frailties; protect us from predators; and help us to find food, create shelter, and use fire. Tools and devices have become so commonplace that they are taken for granted in daily life and are "invisible" as special devices. Most people rarely consider their dependence on some adaptation of the wheel to get around until the car, elevator, or bicycle breaks down. Nor does anyone think about dependence on electricity until the power fails.

People with disabilities are different from other people only in degree. Having a disability means only that one's functional envelope may have less range or flexibility and that one's tools must be designed or adapted to build on existing functional abilities. The daily living needs are the same. The question of "dependence," or the degree thereof, is a matter of perspective.

Building on functional abilities rather than compensating for functional deficits is a paradigm shift. Extending one's mindset about disability beyond "let's fix it" can and often does make the difference between living and just existing. People with disabilities are increasingly vocal about the fact that they do not need to do things as if the disability does not exist; they just need to get the job done. The best approach is the "whatever it takes" model. The message—help me build on my strengths, and not just fill in for perceived deficits—is indeed a different approach to disability services.

TECHNOLOGY: NOT A STAND ALONE SOLUTION

Independence is defined in terms of how much control a person has over his or her environment, not in the number of tasks that the person can do without assistance. Tools have always improved the odds, as has cooperative effort. We are not only tool-making animals, but also strategy-using, social animals; as of-

ten as we have developed a tool, we have developed a strategy to use it and have reached out for assistance from our associates when necessary. In fact, this combination of tools, strategy, and cooperation may be characteristic of humanoid evolution from one level of accomplishment to another. This triad of support can be illustrated graphically by a triangle, each side of which represents one of the aspects of common functional supports (Figure 2–1).

Although the proportions may vary with the particular endeavor, some level of input from each of these three elements is always evident. A particular activity may appear to involve primarily strategy and tools, but cooperation undoubtedly plays a role somewhere. For example, a person who decides to drive across the country alone may consider this a triumph of independent effort: human and machine against the odds. The importance of cooperative effort may recede into the background until the machine needs fuel or the driver considers all the effort that went into building the machine and the road upon which it runs. Clearly, we are all very fragile animals, extremely dependent upon one another, our tools or machines, and our wits for survival.

Despite the fact that everyone relies heavily on this support system, conceptualizing the needs of a person with a disability seems to lead to new "special needs" categories (Figure 2–2). Tools and machinery become "applied technology," "assistive devices," "ADL equipment," "technical aids for the handicapped," or "technological support." Strategies become "adaptive strategies"; cooperative effort becomes "personal assistance services." For people with disabilities, the need for a support system is no less pervasive or necessary than for others, but such a system always includes technological support, adaptive strategies, and personal assistance (people support). Achieving independence means

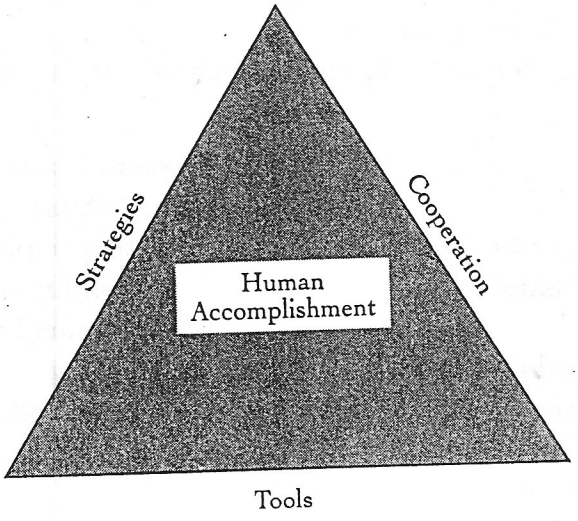

Figure 2–1 Three elements of a human accomplishment support system

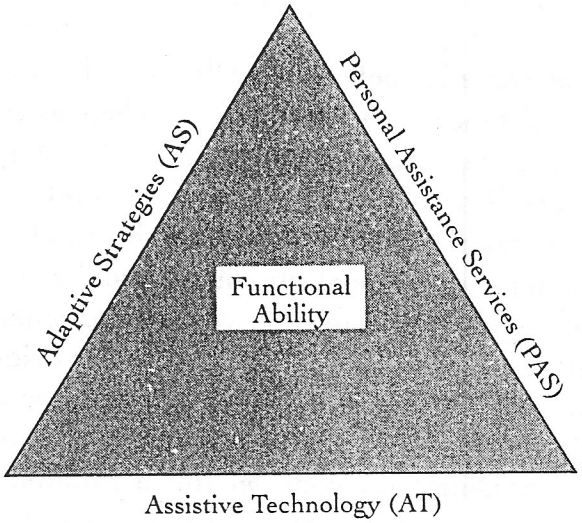

Figure 2–2 Three elements of a functional ability support system

being in control of one's life—defining one's own support system, including the tools, the strategies, and the people support necessary to accomplish any given task or objective, in all the environments in which it is needed.

FEATURES OF A TRUE SUPPORT SYSTEM

A comprehensive list of everyday technology would fill an encyclopedia. In some functional areas, however, tools for daily living may be critical for a person with a disability (Figure 2–3). A few functional tasks, such as lifting, are needed across environments (e.g., work, school, community). It is important to consider these tasks in everyday technology so that the functional solution is unified; for example, the individual should be able to reach out to pick something up in all environments.

Daily living technology includes technological support systems in the following areas:

Shelter:
- Access
- Safety/security
- Environmental control
- Sleeping

Interpersonal relationships:
- Communicating (speaking and writing)
- Sex/intimacy
- Child care

Personal care:
- Breathing
- Eating (input)
- Excreting (output)
- Grooming/hygiene (surface)
- Dressing
- Health management

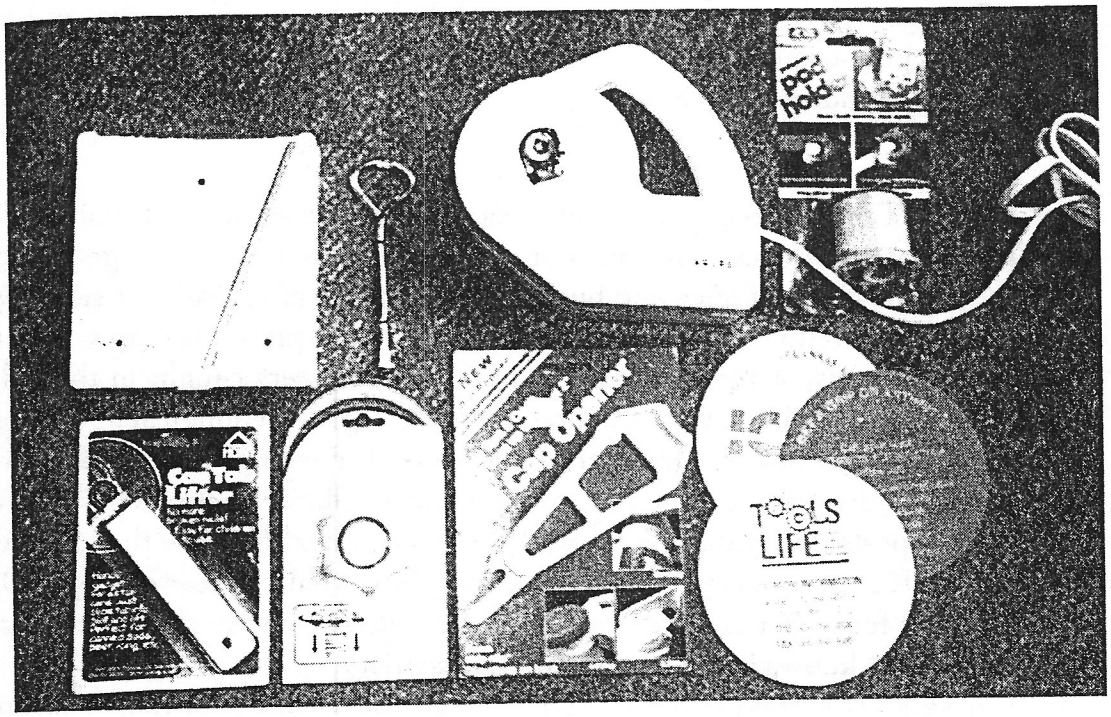

Figure 2–3 Assistive opening devices that come from the grocery store and the hardware store. Round grippers with advertising are freebies from disability programs.

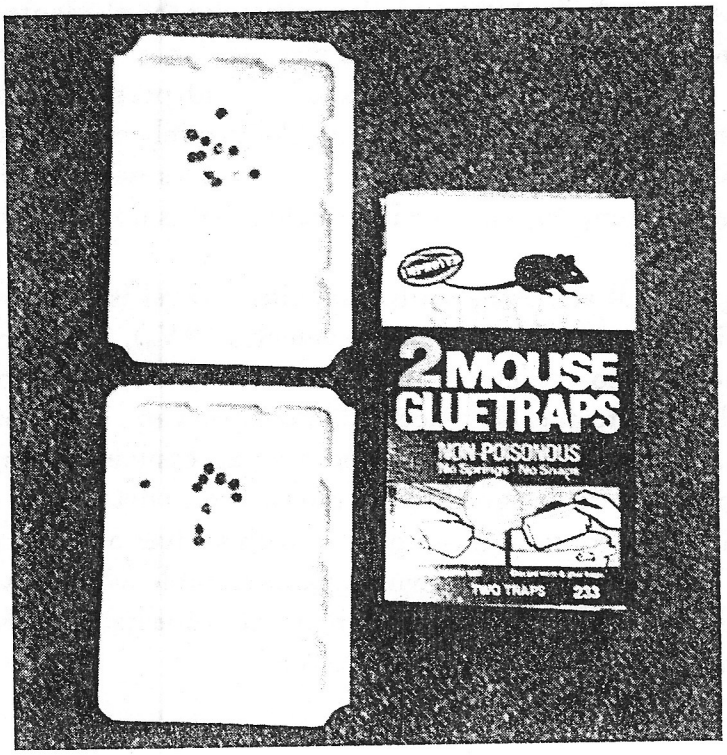

Figure 2–4 Glue traps for tiny game hunting

Home management:
- Storage
- Food preparation
- Cleaning/household chores

Functional tasks:
- Lifting
- Reaching
- Holding
- Transferring

Each of these categories includes many tasks that are not normally included in activity lists and assessments. For example, Figure 2–4 shows a good product ridding the home of mice and bugs. Some people cannot load and set a regular mouse trap. With a glue trap, all they have to do is place the trap where there has been mouse activity—no peanut butter, no fingers caught in the bale, no spring to release if the trap is not set on the floor gently enough. The mouse gets stuck and dies, and the entire trap is discarded. For bugs that are attracted to windows, the traps can be set on the window sill; for cockroaches and other kitchen pests, the traps can be safely set on counters because they contain no poison. It seems unlikely that "mouse trapping" would appear on any ADL assessment form, but anyone who has lain in bed listening to mice chew through the kitchen knows it can be an important activity.

A support system is never static. A functional bathroom that incorporates tools, strategies, and cooperative effort is a jail, not a support system, if the person can use the shower or go to the toilet only at home. The person may need to wash up when traveling or go to the toilet at work. The goal is to maintain the same degree of functional ability, no matter what the environment. Different situations may call for different balances among the elements of a personal support system (Figure 2–5). For example, there may be a fair balance between assistive technology, adaptive strategies, and personal assistance at home. When people travel, however, they are likely to rely more on adaptive strategies and personal assistance. In some places, visitors with disabilities can rent or borrow equipment, formally or informally, that is not readily transported from home.

Recognition that people with disabilities travel is evident in the increased availability of accessible recreation vehicles (RVs). The variation of personal preference is also evident in the range of vehicles seen, from top of the line accessible RVs to the DIY accessible camper/van shown in Figure 2–6. The latter is a van adaptation that includes an accessible cooking set-up. Six-inch deep cabinets were designed to fit onto each rear door. One side houses a fold-down shelf that contains a camp stove with shelves above; the other features a "pantry" covered by a fold-down preparation table with shelves above designed to hold dishes and utensils. Storage bins with rope handles slide underneath the platform, which converts from seat to bed.

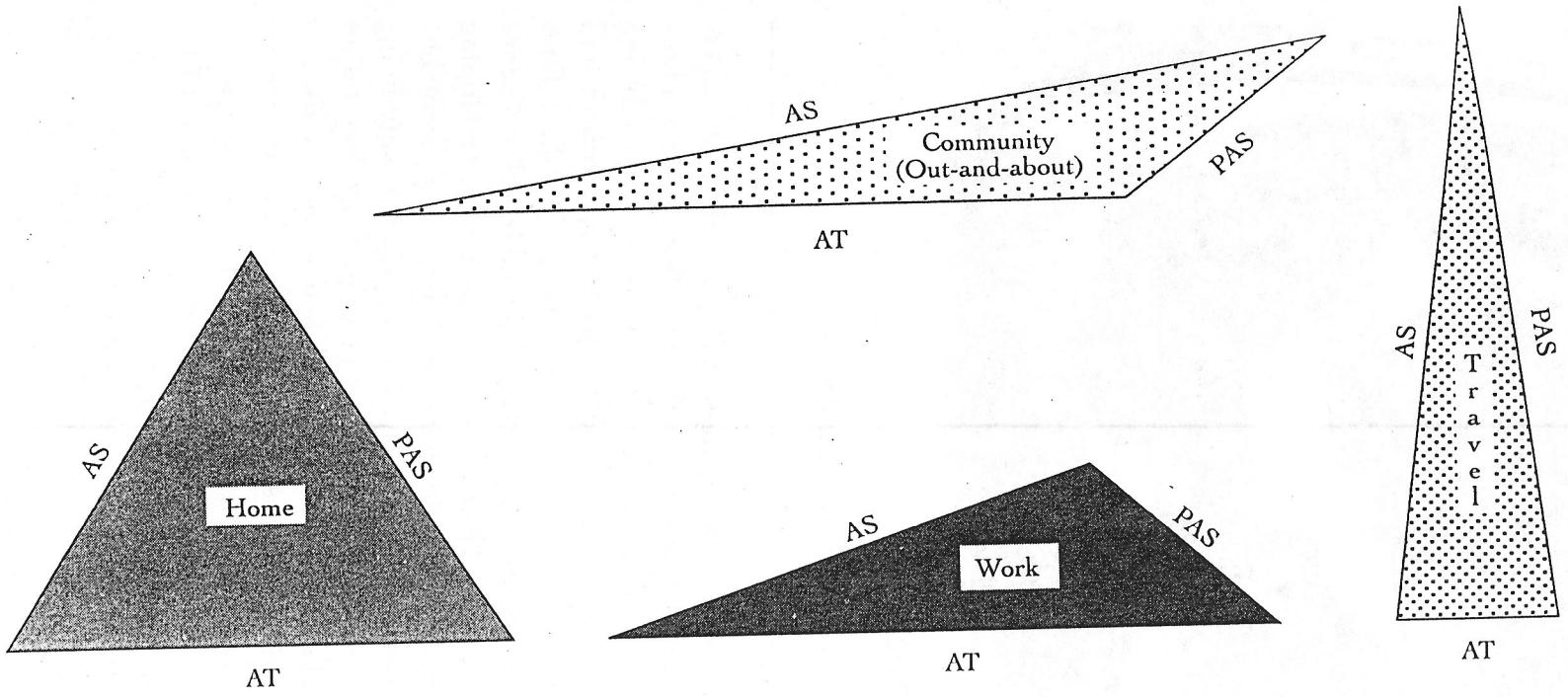

Figure 2–5 Different balances among the elements of a personal support system. AT, assistive technology; AS, adaptive strategies; PAS, personal assistance services.

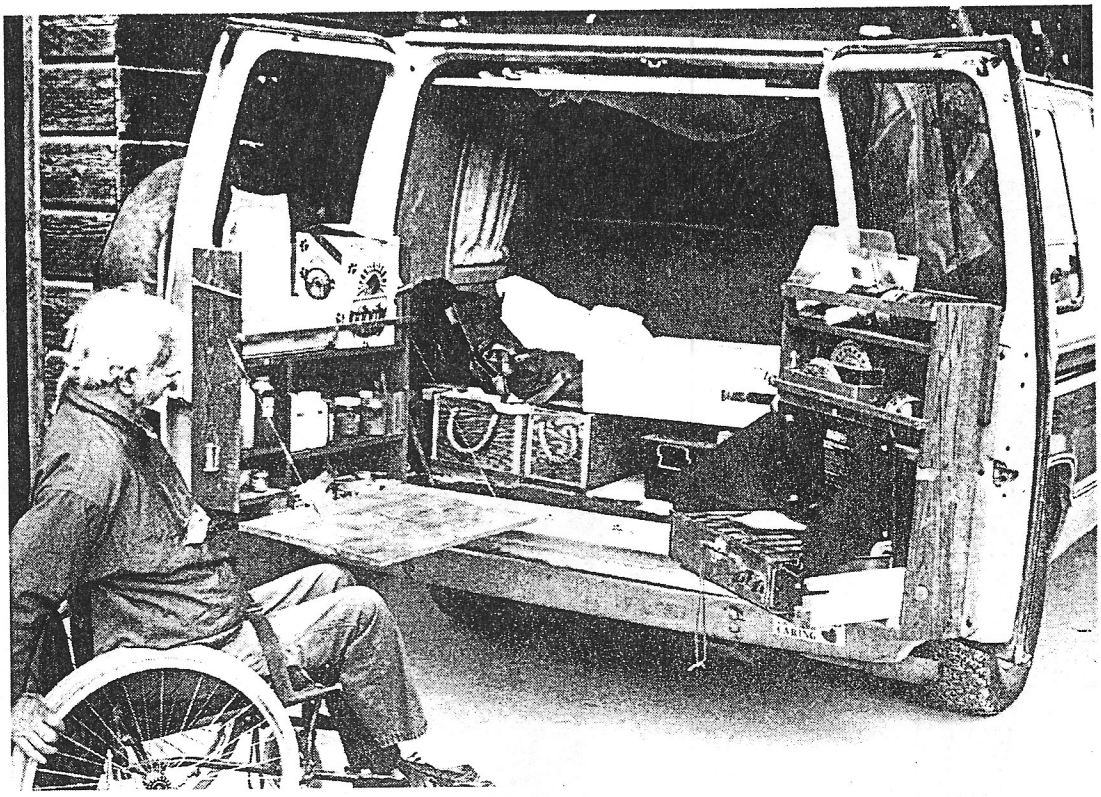

Figure 2–6 Peter Leech's van with accessible cooking set-up

Support systems must take into account changes in functional performance, as well as changes of environment. Changes in medication, fluctuations in hormonal levels (e.g., increased muscle tone and spasticity in some women during their menstrual periods), fatigue level, time of day, changes in strength and stamina that accompany aging, decline in ability related to specific disabilities (e.g., multiple sclerosis or amyotrophic lateral sclerosis [ALS])—all influence the proportions of supports needed. Thus, there is a danger of developing baseline support systems that require a performance level not always available. Although this is true for all assistive technology, it is critical for daily living tools; no one should have to operate at maximum peak performance on an everyday basis. If an individual's ability to transfer independently or assist in a transfer always draws on resources that are very close to maximum performance, provision must be made for those times when this level of performance is not possible. Even people who do not normally use adaptive equipment may need to have it available for days when they are not functioning at their best.

If the technology works only when the "functional envelope" is at its broadest range, there is likely to be a high degree of dissatisfaction among those who use

that technology. Furthermore, those who use it are likely to blame themselves for the failure of the technology. This can discourage an individual with a disability from considering technological solutions again or even from trying to accomplish the task in the belief that the task is beyond his or her skill and capabilities. Norman (1988) described the cycle of technology as learned helplessness. He suggested that the design of everyday things seems almost guaranteed to produce technology phobia. Norman was describing everybody's everyday technology, not assistive technology. People think that the failure is their fault and generalize this to other technology, coming to believe that they just have no aptitude for technology. This phenomenon is probably even more rampant in the disability field, where the marketplace has even less control over good design characteristics.

DEVELOPMENTAL MODEL

A newly disabled person may not at first recognize the challenges in moving beyond a home environment or may not be ready to look for solutions during the early stages of rehabilitation. Because professionals seldom participate in such planning, technologists often see an individual later in his or her career as a person with a disability. At this point, the person may be so used to problem solving alone that the subject of daily living issues does not arise. That does not mean that everyday technology should be overlooked, however.

Function Away from the Primary Environment

The support system required to achieve independence will vary with the distance and length of time a person can stay away from his or her primary residence. If a person's reentry into life and community is to be accomplished with any efficiency, the support system must include the useful tools, strategies, and cooperative effort associated with the common ADLs, especially when it is necessary to accomplish them away from the immediate residence. The most efficient support system involves people with a similar disability who have managed to reach a higher level of independence so that the newly disabled person loses less time in "reinventing the wheel." This element of peer counseling is often overlooked.

After learning to function in their primary environment, people begin to want to venture away from it. Whether a woman who has a mobility impairment, for example, can go out depends on her mobility and access. Given a functional manual wheelchair or a reliable power wheelchair, adequate ramping, and wide

enough doorways, she may begin to test her ability to function in the yard or on the street. How long she may venture away depends on her ability to manage eating, drinking, and bladder and bowel functions away from her primary environment. This often requires either that different strategies be employed in order to function in the absence of a support person or that a support person go along for the ride.

It is essential to test a person's ability to function in each one of the daily living areas away from the primary environment before that person can begin to consider the demands of education, vocational training, or employment. Being away from the primary environment from early morning to evening on a daily basis also necessitates modification of the self-care regimen at home (e.g., bathing, grooming, bowel care, dressing) so as to be accomplished before or after the day away. If in need of personal assistance for these activities, then the person must have control over scheduling.

Personal Technology

Touching every aspect of daily life, tools for living can be highly personal—especially when they involve basic body functions. It can be difficult and embarrassing for everyone to discuss the intimate details of bladder and bowel function, menstruation, sexuality, and personal hygiene, for example. There are privacy and confidentiality issues. Even more important are the vulnerability and emotions associated with changes in function or in ways of handling such personal activities.

There is not even commonly accepted language to ease the awkwardness of such discussions. People may write down bladder function and talk about urination, but most still say "pee." In 1994, Enders planned an informal discussion group at a national technology meeting, "Going with the Flow: Peeing and Bleeding for Women and Very Enlightened Men." The announcement of the session and the language used caused quite a stir. It is critical to find appropriate ways to talk about these issues.

Apparently, it is difficult even to write about some areas. For example, there is almost nothing in the literature on menstruation except in the English book *Disabled Eve* (available from the National Rehabilitation Information Center, 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910). The few references that do exist provide little detail on the physical manipulation of female sanitary products. A tampon inserter is commercially available in England, but none is readily available in the United States. This is not an obscure issue—half the population deals with the issue of menstrual bleeding and hormonal flux for at least 30 years. A DIY solution is shown in Figure 2–7. When tampons on a stick

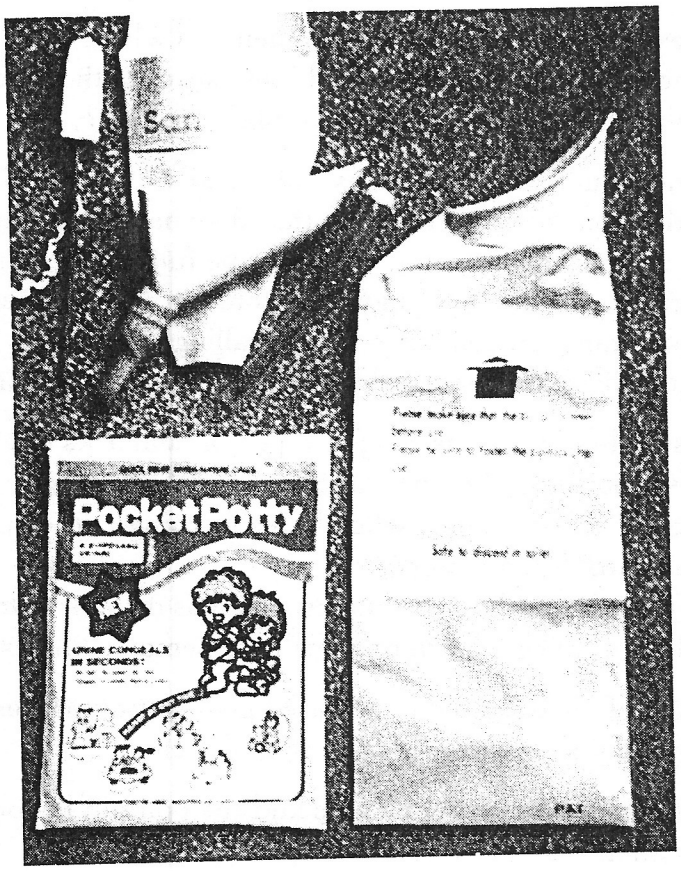

Figure 2–7 Funnels for urination. Do-it-yourself tampon inserter, top left

were no longer commercially available, a consumer started making her own by inserting a thin plastic paint brush handle into an OB brand tampon. She stresses the importance of placing a washer or something similar on the handle to prevent it from moving all the way through the tampon and coming out the far end during insertion. The handle can be washed and reused. This woman also uses a carefully planned adaptive strategy for inserting and removing the tampon.

Differences in comfort levels and in values (e.g., attitudes about birth control, sexual orientation) come into play when intervention is needed. Although a nurse may be very comfortable discussing body functions, some technologists may be uneasy in such discussions. If the professional is uncomfortable, it will be very difficult for the person with a disability or a family member to bring up these issues. It is critical to recognize one's personal comfort level. If discussions of such issues as toileting, sexuality, and tampon insertion create embarrassment for either the individual or the professional, another team member, a peer counselor, or an outside referral may resolve the problem.

SELECTION OF APPROPRIATE DEVICES

- What does the person want to do? When and where?
- What functional abilities, skills, and interests does the person have?
- What tools can best be used to accomplish the task?

Assessment, formal or informal, is one means of determining consumer needs. Depending on the length of time that they have had a disability, people may need a traditional assessment, they may be full partners in identifying issues and solutions, or they may have the solution worked out and just need assistance in obtaining, customizing, and installing equipment. The differences in these circumstances are comparable to the differences in working with

1. a dentist, who does something to a person and asks questions while the person's mouth is full of instruments
2. an educator or counselor, who shares learning and discovers a process for future problem solving
3. an architect or building contractor, who has demonstrated expertise and is hired to produce a product, which the person controls and pays for

Whether part of an assessment, a shared goal-setting process, or a contractual relationship, information gathering should include:

- data on the person's current status and the point in his or her career as a person with a disability (see Developmental Model)
- any expectations of change in the person, resources, or environment;
- identification of the person who wants change to occur
- the basis on which success will be evaluated

This information is necessary for all technology interventions. The approach used depends on where and when the professional is called into the process. The issues may reflect a global need, such as opening and closing doors in all environments. Sometimes, the person needs recommendations for a specific environment, such as the home bathroom or kitchen. Sometimes, the professional is asked to look only at possible applications of assistive technology, while others consider alternative options and pull the process together. Sometimes, the technologist is called in after everyone else has given up, in the hope that technology can solve the problem.

When looking at everyday technology, it is important to understand why the individual seeks intervention at this time. These activities usually have been occurring everyday for some time. What is different now? Have expectations been raised (or lowered)? Have functional skills changed, and are they now stabilized or is more change expected? Has an essential element of the person's overall support system changed (e.g., a personal assistant is leaving)? Will the

environment change (e.g., the person is leaving for college)? Has other technology caused a change (e.g., a new wheelchair causes a problem with bed and toilet transfers)? One of the founders of the Independent Living movement told the story of being motivated to find a way to control a power wheelchair when he fell in love; he decided that having an assistant along pushing his wheelchair was not conducive to a romantic relationship with his girlfriend. The reasons for a desired change in everyday technology are not always as straightforward. A mother who is looking for a better way to help her 14-year-old daughter with cerebral palsy in the shower may really be looking for ways to handle her daughter's menstrual periods in a manner that is acceptable to both of them. The teenager may be bigger and heavier, and may have outgrown her current bathtub equipment, but only probing questions such as "why does she need more showers now than she did 2 years ago?" are likely to lead to an acceptable solution.

Problem identification should incorporate all the aspects of the functional activity, not just a specific and isolated task that has been focused on as the problem. Keeping the questions "what's different?" and "why now?" in mind can help. Sometimes, when the individual recognizes what the real issue is, he or she or a family member can readily solve it. Sometimes, understanding "why now?" suggests a more appropriate professional relationship. For example, a woman who wants to change because she saw someone else doing an activity and thinks she could find a way to do it, too, may be ready for a partnership/problem-solving model or an introduction to peer mentors.

CRITERIA FOR EVALUATING EVERYDAY TECHNOLOGY

Even though applied to the same range of human activities as are other tools, assistive technology devices are often evaluated by different criteria. The only real difference, however, is that they may need to address a larger or more varied degree of limitation. This does not seem a valid reason to treat them as a special category of tool or to judge their performance, economics, or aesthetics by less rigorous criteria than those applied to other tools.

If it is to be effective, any tool must succeed on two counts:

1. **Technical features**
   Does it work?
   Is it strong and safe?
   Is it compatible with other equipment?
   Is it reliable?
   Is it durable?
2. **Ergonomic (human factors) features**
   Is there a feeling of security when using it?
   Is it simple to use?

Is it the correct size?
Is it comfortable?
Is it aesthetically appealing?

The technical features can be objectively measured; the ergonomic features are more subjective and should be evaluated in relationship to the device user and/or caregiver. If an elderly woman does not feel secure on her elevated toilet seat, for example, she probably will not use it. Surveys in the United States (Grall, 1979) and England (Page, 1981) have shown that adaptive equipment often does not measure up very well to these standard criteria for useful tools.

To ensure that they are not using a double standard, professionals who use, build, prescribe, or recommend equipment for an individual with a disability should apply one question to every piece of equipment: "Would I want this piece of equipment in my house, my office, my car?" If the honest answer is not "yes," then it is time to go back to the drawing board or the file cabinet and look for another solution. An additional set of functional criteria can be called the "closet test" in answer to the question, How do you keep equipment out of the closet? These questions are implicit (or should be) in the purchase of any product. Because equipment decisions are not always in the control of a person with a disability, outside "helpers" or developers may need to be reminded to address questions such as the following:

- Would I want this thing in my house?
- What impact is it really going to have on this person and his or her family?
- Is it worth the effort to use the device?
- How labor-intensive is it to set up, fit, clean, maintain, and store?
- What options does the person have if he or she does not use this thing?
- What incentive is there to use it?
- What disincentives are there?
- Is it possible to get by with less, to reduce the overall number of devices?
- Does the person need more? Is this just one piece of a system?
- Who will do routine maintenance? Do repairs?
- Where will it be stored when not in use?

A whole field of questions relate to the theme, "Would I want to use this thing?" Questions will be specifically different for each type of device, but the general tone is

- for an eating device: Would I use it in a restaurant?
- for adaptive clothing: Would I wear this in public? On a date?
- for a transfer device: Would I use it in public?

FINDING INFORMATION, SERVICES, RESOURCES, AND PEOPLE

There is no great mystery about assistive devices; they are just tools! People who are unfamiliar with the way tools work, however, may need to learn that all tools or machines are simply combinations of mechanical, electrical, or electronic devices arranged in a way to accomplish a certain task. Once they can relate their assistive technology to the technology that already exists in the community, people with disabilities can develop their own "circles of support" to attend to their assistive technology needs. Rather than formal dealers and repair services that are inconveniently located or unavailable altogether, local service people can repair the mechanical, electrical, or electronic components of most assistive devices; others can invent and fabricate special devices when asked to do so. These are the same people who keep the other tools and machinery of modern life up and running. They can keep people with disabilities up and running as well.

When approaching nontraditional service people for repairs or maintenance on assistive devices, it is important to ask questions that fit within their frame of reference. For example, it is appropriate to call a welder when the frame of a wheelchair needs repair, but rather than ask whether the welder "repairs wheelchairs," it is more useful to ask whether he or she can weld the metal of which the wheelchair is made (e.g., stainless steel, chrome-moly, aluminum). This, of course, requires that the person with the disability be familiar with the equipment and its component parts. Other possible questions might include, Can you check the charging capacity of a deep cycle battery? or, Can you check my machine for a short circuit or a defective switch?

Asking a helpful hardware dealer for assistance with a DIY project can have unexpected benefits. For example, when Leech wanted to set up a sprinkling system that he could turn on from his porch (Figures 2–8 and 2–9), he asked a hardware dealer about outdoor water faucets with lever handles. The discussion that followed not only yielded the faucets, but a great deal of other useful information about what size plastic pipe to use, how to fit it together, and what sprinkler heads are best and how to install them. Often, hardware dealers know other people who can be helpful with a project.

It can also be useful to investigate what else has this component or something like it? Leech spotted a wheelchair ramp in another city that had an open-wire mesh covering so that snow could pass through it. This seemed like a good idea, so he called a building supply store and talked with someone there about what the material looked like, the usage that it would get, and the weight that it had to support. He learned that an extruded steel mesh would do the job and built that into his ramp plans (see Figure 2–9).

Figure 2–8 Peter Leech turning on the top faucet lever on his complex watering system

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In the mainstream consumer marketplace, in a specialized part of it, or in a specialized industry, there may be someone who needs to do exactly the same thing. For example, pilots and passengers in small planes that do not have toilets may have some creative suggestions about what to do when they need to urinate. Function-oriented features may appear in product literature, and knowledgeable salespeople can help. Usually, there are no features labeled "access" or "handicapped," as manufacturers do not yet understand this market. Even when there are such labels, the features need careful examination for utility, because manufacturers sometimes use a very narrow interpretation of access.

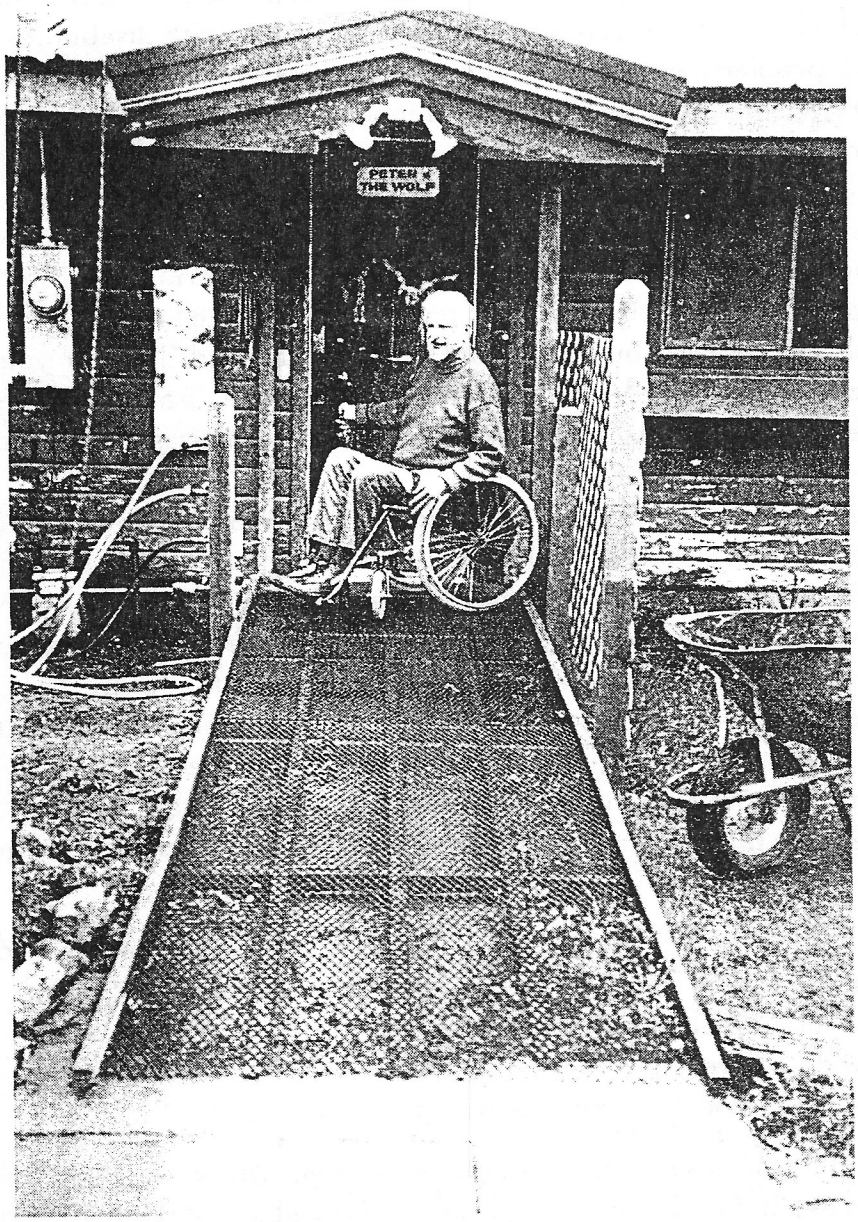

Figure 2–9 Ramp useful in snow. Watering system controls on left post.

Developing a People Network

People with Disabilities As Information Resources

Professionals need to recognize that people with disabilities can be excellent sources of practical information. Too often, professionals who work in traditional settings have contact only with people who are newly disabled or who are having major medical problems. Because they rarely have the opportunity to

interact with healthy people with disabilities who are successfully going about the basic business of living, they can forget that people with disabilities who are *not* having problems even exist. When their professional lives focus on people with problems, it takes some adjustment to focus on people with solutions. This shift is critical, however. Fortunately, it is easier to make this shift today, since there are so many more people with disabilities out and about in the community.

The first step is to ask questions! It helps to be curious and outgoing, but honest interest generally elicits a willingness to share information. Both authors have stopped people with disabilities on the street, at the farmers' market, and at the mall and asked them, "Where did you get that?" and "How do you use it?" It is somewhat easier for Leech to do this, since he has a disability himself and is recognized as a peer, but Enders also gets positive responses and has never had anyone refuse to talk to her.

Similarly, professionals may ask people with disabilities in the community whom they meet by chance at a health care facility, in a training program, or at a store, for example, about how they are successfully doing other things. It is helpful to collect their stories, write down their useful ideas, including the source and date. If they are willing to be contacted in the future, they can become part of a pool of peer mentors, in-service speakers, and other types of advisors. Such questioning may benefit people with disabilities personally by keeping them from slipping into a passive patient mode and helping them to remember that they have good ideas and successful strategies. Some questions to ask include

- How do you _____? (Fill in the blank; ask about something different from the reason that they are visiting the center, office, or store.)
- What other technology do you use?
- How do you reach your _____? (Fill in the blank; ask about areas that may need to be dealt with creatively.)

If the people with disabilities do not think they use any technology, the professional can expand definitions of technology and ask about regular mass market products that they find useful; if possible, the professional should get the brand name and model number of any device they find useful, where they purchased it, and how much it cost.

People with Disabilities as Mentors

People with disabilities also need to recognize that they can often get good practical information from their peers. They need not always turn to professionals for information and ideas. Furthermore, people with disabilities who have developed a repertoire of satisfactory supports should make an effort to educate

professionals by going back and talking to former therapists and doctors. Finding people with disabilities who have solved problems can be difficult for professionals.

With a curiosity about how things work, a willingness to go looking for people, and a genuine belief that people with disabilities have information and are good problem solvers, a person with a disability can cultivate a network of enthusiastic people with disabilities who are willing to share information. These people can be a resource for other people with similar issues:

- to provide information
- to see how their system works
- to let other people with disabilities try out their ideas
- to act as role models

Circles of Support

If independence is the objective, people with disabilities must have the circles of support that they need to function at as high a level of independence as possible in home, family, and community life. Beyond family and friends, this circle may include the local senior center, a special education teacher, a local repair person, another person with a similar disability who has learned to function independently, and any other specific service that the particular person needs.

This system of support is really no different from the one that has long existed in rural areas. Although perhaps not organized in the same way as urban services, people in local, rural communities can fabricate, repair, and maintain tools, equipment, and machinery; there are electricians, machinists, woodworkers, metalworkers, and welders, as well as hardware dealers, county extension agents, and others who know how to contact these people. This type of support system has not traditionally been used to provide service for people with disabilities, in part because of the mistaken belief that the needs of people with disabilities are unique and can be satisfied only by professionals.

Described graphically, a circle of support has the person with the disability at its center. Located around the center are the person's family members, friends, and local resources (e.g., the repair person, the Lion's Club, the person's church, or the grocer). For more complex challenges, a second circle can surround the first; it represents regional resources, such as the vocational-technical or community college, a vocational rehabilitation counselor, an occupational therapist, or a regional outreach center. A third circle may represent other state or federal service programs. This system is dynamic in that as day-to-day needs change, a person may call different resources into the first circle of support.

ASSISTIVE TECHNOLOGY: WHERE IT CAME FROM, WHERE IT IS, WHERE IT'S GOING

To be effective, the full range of everyday technology should be approached as an integral part of an ongoing support system, used when needed and available, neither considered *the* answer nor tagged on as an afterthought. It must be considered in relation to adaptive strategies and personal assistance services and within the various environments in which any person's support system must function. Technology failures are more often a failure of the delivery system than of the devices themselves. A large number of devices are available, and many innovative products are about to enter the market. Whether devices and adaptations are used, how they are used, when they are used, and why they are used are often related more to the attitudes of professionals and policymakers than to the functional features of the hardware or to the needs of people with disabilities. Resource allocation decisions not only control the availability of third-party payment and/or provision of technology, but also have a powerful impact on the information that reaches consumers.

Several studies (e.g., Manton, Corder, & Stallard, 1993; LaPlante, Hendershot, & Moss, 1992; Longino, 1994) suggest that people are increasingly aware of and are actually using more adaptive equipment. If the more specialized equipment saw an increase in use, it seems likely that the common, easier to find, and less stigmatizing devices also saw more service. Many of the people in a Toronto study on caregiving for people with Alzheimer's disease were, in fact, initially reluctant to be interviewed because they said that they were not using any technologies (Darjes, 1990, p. 4). When the interviewer went through the list of devices, however, everyone was using at least one; most were using five or six. The "devices were so much a part of their daily lives that they didn't think of them as 'technologies.'" This type of equipment is often what McCuaig and Frank (1991, p. 228) referred to as "transparent equipment, that is, conventional items, commercially available, that could be considered adaptive because of their specific characteristics and application."

Assistive technology devices often adopt the principles of universal and transgenerational design. People buy them even when they are a little strange looking, because they appear to be easy to use and useful. Longino (1994) postulated that "fringe products" will increasingly enter the mainstream marketplace. This is evident as adaptive bathroom equipment is beginning to appear at discount stores like Home Depot and Best, adaptive telephone equipment at Radio Shack, and safety rails at the local hardware store. Manufacturers are coming to recognize that people with disabilities constitute a market that can be reached through mainstream selling sites and strategies.

Wolff (1972) called the project "of utilizing minor technology" Unexciting Research into Necessary Equipment (URINE). Unfortunately, many disability

researchers feel that URINE is an appropriate name for product development and research into everyday technology. It is not quite accurate to say that the research is not exciting, because a breakthrough is very exciting. Breakthroughs tend to be the result of real creativity, frequently outside the realm of the originally planned research. The best "labs" are usually in the homes of tinkering people with disabilities.

The best way to develop accessible aids to daily living products may actually be by increasing the awareness of product design professionals. Realistically, most of the significant advances in daily living aids for people with disabilities have been mass market products and services: modular environmental control units available at the hardware store, automatic garage door openers, microwave ovens, bidet type toilet seats, waterbeds, edible TV dinners and other convenience foods, food processors, oven rack pullers, automatic dishwashers, home security systems, Niagara beds, Velcro shoe closures, jogging clothes as acceptable streetwear, vibrators, hot tubs, hand-held shower massage units, electric toothbrushes, electric can openers, remote controls for almost everything, and on and on. Until the architects and product designers incorporate universal product design into the total environment, however, people with disabilities will have to look for more immediately available forms of technical aids to retrofit personal environments and everyday technology.

CONCLUSION

For everyday technology, the changes in equipment for people with disabilities are probably less important than the changes in the process. The best way to retrofit everyday technology is with a self-help approach to problem solving. Do-it-yourself is more a process than a product or technique. Once people learn to explore a wide range of potential resources and develop a broad view of how and where technology can assist in everyday life, self-help and the process of everyday DIY technology become routine parts of independent living. This ability to take control of the technology is a powerful starting point in breaking the dependency cycle that is inherent in so many disability-oriented services.

Do-it-yourself is not really a matter of how many things one can saw or solder, but how one manages the everyday tools of living. The biggest challenge is to incorporate both professional and self-help approaches into a support system that is flexible and adaptable in multiple environments over time.

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Appendix 2–A

A DIY Process: Food Preparation and Nutrition

Good food preparation is the cornerstone of the good nutrition that is necessary to maintain good health and avoid the secondary illnesses that interfere with an active, independent life style. Food preparation actually involves a number of separate, even though interrelated, tasks, all of which must be subjected to the same scrutiny as any ADL. A person with a disability should ask:

- Can I do it myself?
- Can I learn some new adaptive strategy to make it possible?
- Will some tools/assistive devices help me to do it?
- Do I need people-help? If so, how much?

The tasks include planning the meal (e.g., reading cookbooks, checking resources), shopping, transporting foods home, storing foods prior to preparation, cooking, serving, storing leftovers, and cleaning up.

PLANNING THE MEAL

What do you like, what's good for your body, how much of it, and how often? What do you have to prepare, cook, and serve with? Stove, refrigerator, pots and pans, utensils, serving dishes, plates, cups, utensils, etc.?

What does it require to prepare this food? Knives: size, shape, sharpness? Cutting board? Bowls: how many, what size, ceramic or metal? Trays, plates, platters? Spoons: size, shape? Food processor or mixer?

What does it require to cook this food? Burner or oven? Sauce pans, sauté pans or skillets, lids, larger pots, baking pans? How many, what sizes?

What does it require to serve this food? Bowls, platters: how many, what sizes? Plates: how many, what sizes? Tableware? Glasses?

What will be necessary to store and use the leftovers?

All these questions make cooking seem like an overwhelming task; therefore, it is essential to start out simply. When I started cooking again after becoming disabled, I learned very quickly that I could continue to use only a few of the things that I had used before: a griddle with a bail handle (a heavy wire handle), a certain knife that fit the way my chopping/cutting hand works, and large bowls made of plastic rather than heavy ceramic or glass (I dropped and broke most of those before too long!). Over the years, I have learned from these experiences and now can fairly easily select those utensils that will work for me.

SHOPPING

Where should you go to get the things that you want? Are those places accessible? Do you need help? What form should you purchase (e.g., fresh, dried, boxed, bottled), and how do you carry these things home with you? Generally, fresh fruits and vegetables weigh less than bottled, canned, or jarred items, but there are some things that you can find only in the bottled, canned, or jarred form. You should be prepared to deal with these as necessary in order to follow the dictates in your meal planning. If you limit your shopping because you cannot open cans or jars or because you cannot lift their weight, you may be limiting your nutrition or palate unnecessarily.

TRANSPORTING FOODS HOME

Getting your purchases home requires lifting and carrying, unless someone else is doing the shopping. The store clerks can pack your groceries in manageable units, several bags if necessary, balanced so that *you* can lift their weight when you get them home. Checkers generally ask whether customers want paper bags or plastic. Environmental concerns aside, I have learned to say, "Both." A large paper bag *inside* a plastic bag gives the plastic bag shape and stacking ability, and the plastic bag has the handles and strength to be lifted, one-handed, as long as it is not loaded too heavily. It can take some trial and error to figure out just what works, but that leads to adaptive strategies. This approach is a great learning experience for managing independently, either doing it yourself or deciding where and when you want to get help because the time : energy equation does not work for you.

STORING FOODS

Foods need storage in two forms: as ingredients or stock items before the cooking and as leftovers after the cooking. Almost invariably, some form of re-

frigeration or freezing is necessary to preserve the leftovers safely. Many types of storage bags and containers are available for these purposes. The reusable types are most desirable as long as they are workable for you. I prefer 1-quart and 1-gallon zip-lock bags for those things that I can enclose and lay down on the table so that I can "zip" by running my thumb along the "zipper." I recycle these bags as often as possible. For plastic containers, I look for those with a stiffening ridge around the bowl and lids that have a ridge around the top so that I can use my teeth and bite to accomplish the final closure. This configuration also facilitates the opening after they have been refrigerated and the cooling of the air has created a vacuum inside.

Jars are notoriously difficult to open for persons with diminished hand strength. There are two possible reasons for this difficulty. The jar may be fresh from the packer, and the *vacuum* resulting from the packing/preserving process is very strong; or the jar may have been opened, and the residue of sticky contents between the jar's edge and the lid, and the vacuum resulting from refrigeration and the cooling of the air inside, have combined to create both a mechanical and a vacuum seal. Many "jar openers" have been devised to make up for diminished hand strength, but most of them require hand strength to operate. The only one that I have been able to get to work for me consistently is a little known, but very effective "trick" that releases the vacuum so that the lid can be turned with relatively little hand grip and twist effort.

A tool that can pry out the lid just enough to release the vacuum is available from many paint supply dealers. Known as a paint can opener, it is actually a beer bottle opener (for the painting parties) with a flat hook on one end (to open the paint cans). The hook end of this tool can be slipped under the edge of the jar lid and the lower threads on the jar and used to "pry" the lid away from the jar (Figure 2–A–1). You will know that it is working when there is a hiss of air being sucked into the vacuum of the jar and a pop as the safety button on the lid pops up. The lid may then be turned with minimal hand strength. It sometimes takes several tries to find the exact spot between the lid and the threads that will afford the proper leverage to release the vacuum; it is best to start with the lowest threads and work upward until you find the right place to pry. With a little practice this procedure works every time. When a residue has been allowed to dry on the lid, creating a mechanical friction, you may also have to rinse with hot water under the rim to loosen the lid. The warming caused by standing the jar upside-down in the sink and running hot water down onto the lid edge may also release the vacuum. A few of these experiences will help you to remember to clean the rim of the jar before resealing. I have also used the rounded end of a table knife and the handle of a spoon to accomplish the prying when I have not had a paint can opener available. Anything that can fit into the threads will do.

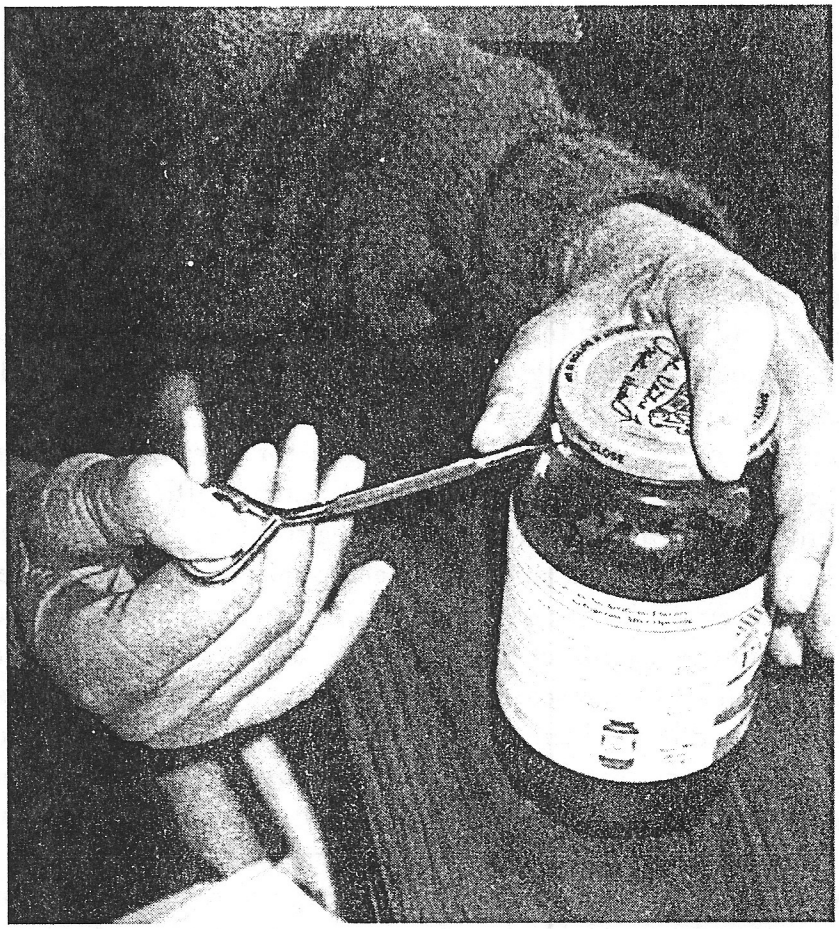

Figure 2–A–1 Paint can opener used as a jar opener

COOKING

As mentioned earlier, the tools available for cooking are so numerous and varied as to be overwhelming. It is essential to start simply and add to your cooking arsenal and repertoire slowly. Utensils must fit your strength, stature, and hand strength. Deciding the kinds of things you want to cook and examining the operations necessary to accomplish this determine the utensils required.

I select knives that are relatively lightweight and balanced so that the handle is about as heavy as the blade and has a shape that hooks down into the soft part of my hand between my thumb and forefinger. I cannot really grip the knife, so I balance it in the crook in my hand and guide it while the weight and sharpness do the cutting.

I choose pans that have flat handles. I do not have to grip this kind of handle in order for the pan to stay upright. For larger pans, I choose the flat handle plus a loop handle opposite the "sticky-out" handle so that I can lift it with both

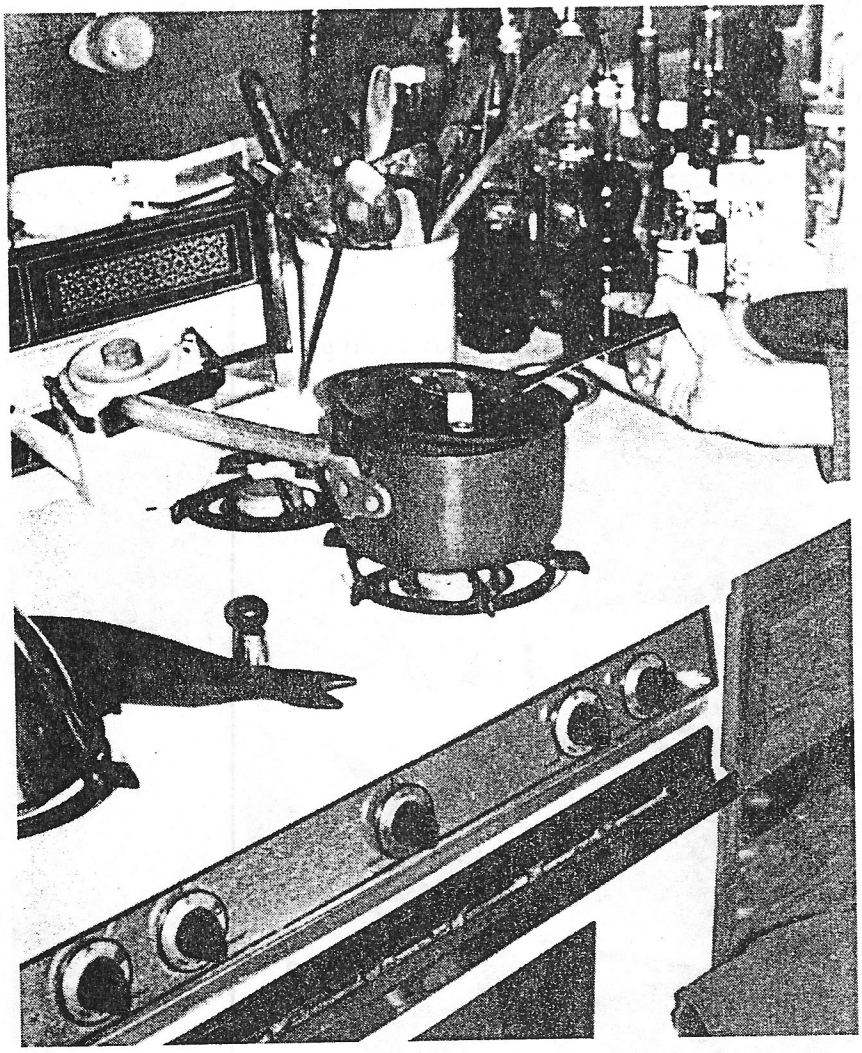

Figure 2–A–2 Flat-handled pot with loop handle on opposite side. Spoon used to lift pot lid

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hands without having to "grip" it. For larger "stock pots," I choose those with two loop handles for the same reason.

I can lift lids that have a flat loop handle with either a hot pad or a towel around my fingers, or I can use a spoon as a lever handle and lift the lid to set aside (Figure 2–A–2). Of course, the spoon that I use to lift the lid also has a flat handle, so I do not really have to grip it to balance the lid. In fact, most of the cooking utensils that I use (e.g., spatulas, spoons, serving spoons) have flat handles for the same reason.

I have learned that stainless steel bowls are lighter and do not break as easily as glass or ceramic. They are economical in that it is not necessary to replace

them often. (Mine have lots of dents.) Over the years, I have collected an assortment of sizes and shapes.

I have a very "open" kitchen, carved out of a very compact space. I have had the doors and shelves under the sink taken out for "turn-around" space between the sink and the stove, and the hinged doors taken off the lower cabinets so that I can reach sauté pans and pots without acrobatics (Figure 2–A–3). Ingredients, herbs, and condiments are on open shelves or counters where I can reach them easily. Some lighter pans and utensils are on a (low) overhead rack where I can reach them from the preparation table that I use (Figure 2–A–4). Currently, this is a simple folding table that I can get my knees under and get close

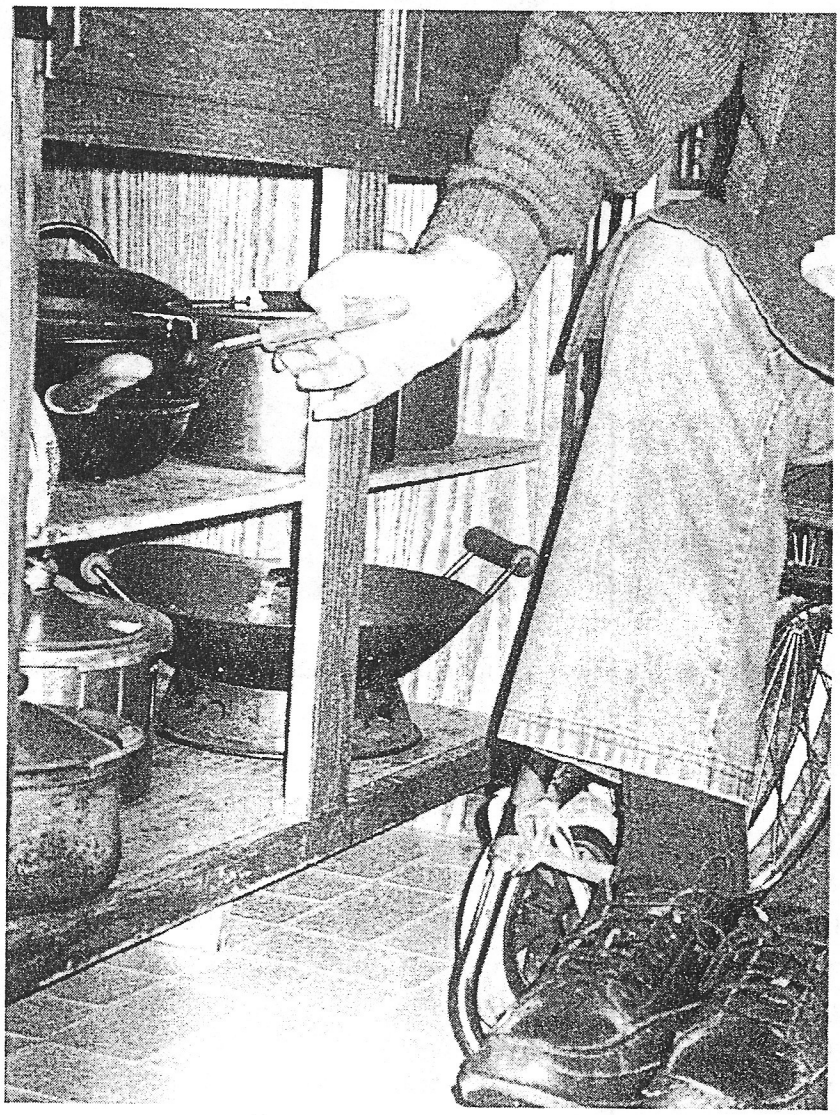

Figure 2–A–3 Shelves without doors to allow access to pots and pans

Figure 2–A–4 Low overhead rack for lighter pans and utensils. Loop handle on pot allows easy gripping

enough to use for chopping vegetables and preparing other parts of a meal. I can reach things at the back of this table. My food processor, knife sharpener, and mixer are on a fiber pad or towel so that they slide easily to the front of the table when I need them, yet are stable during use (Figure 2–A–5).

I use a simple flat board on my lap, covered with a folded tea towel to carry things. After I chop things, I slide them off the cutting board into a light wooden

Figure 2–A–5 Meal preparation area

bowl or plate to transfer them to the cooking pan on the stove (Figure 2–A–6). These wooden bowls and plates are available at Cost Plus and other Asian import stores.

I sometimes cook for larger groups and have learned to store the larger cooking and serving items on the higher shelves. After all, the only time I use them is when there are other folks around who can get them down (and clean) and put

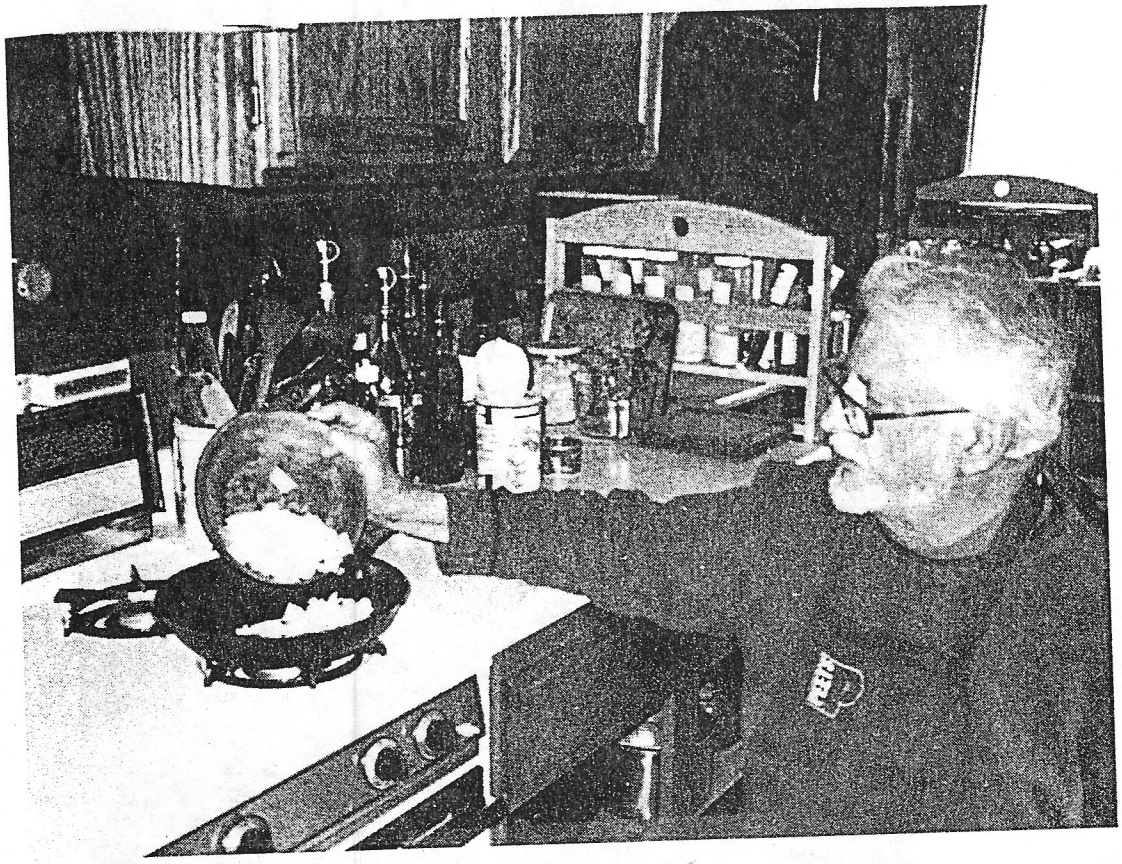

Figure 2–A–6 Using wooden bowl to transfer chopped food to cooking pan

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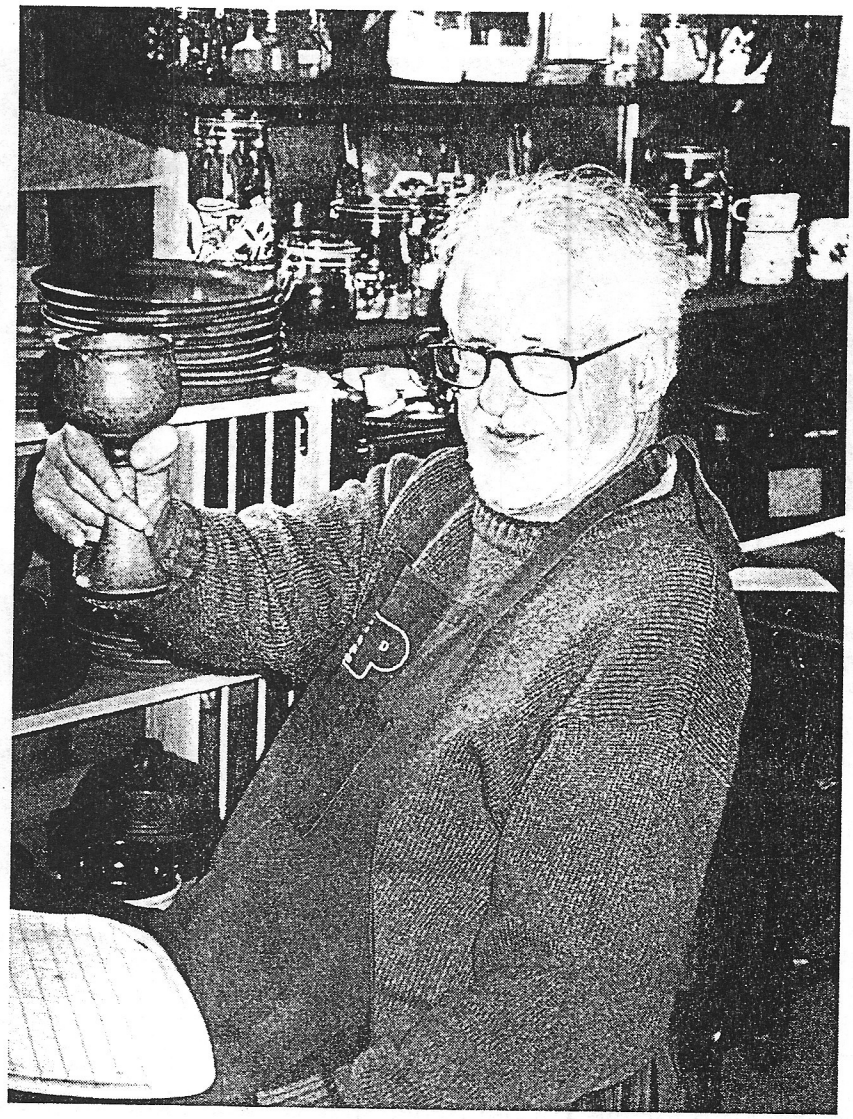
them back up for me. So the upper shelves of my kitchen are decorated with these items. Usually, people are willing to trade their energy in preparation and clean-up for my experience and creativity in the cooking, and the end result is a sense of equal sharing.

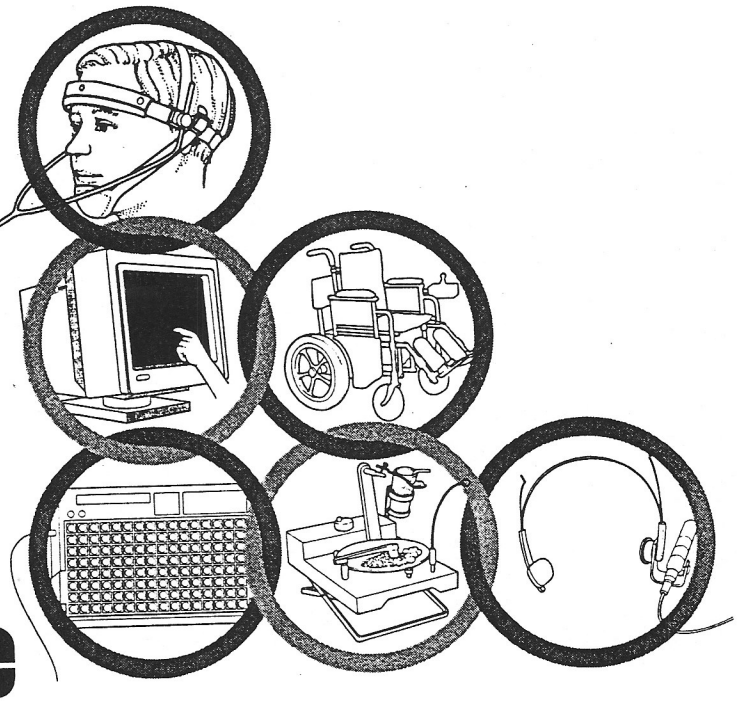
Bon Appetit!



Fig–2–A–7 Bon appetit!

There are many other DIY projects that I could describe here that would contradict the commonly held view of what a person with a disability is capable of or interested in. In workshops, I have described myself as a father, a lover, a photographer, an artist, a winemaker, a flyer (of light airplanes), an organic gardener, a vegetarian gourmet cook, and what have you! I identify as a "person with a disability" only in a political sense and reject the idea that my physical limitations render me "dependent" in the popular or common view of people with disabilities.

Peter Leech



Evaluating, Selecting, and Using Appropriate Assistive Technology

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AN ASPEN PUBLICATION®
Aspen Publishers, Inc.
Gaithersburg, Maryland
1996

Library of Congress Cataloging-in-Publication Data

Evaluating, selecting, and using appropriate assistive technology / [edited by] Jan C. Galvin, Marcia J. Scherer.
p. cm.

Includes bibliographical references and index.
ISBN 0-8342-0664-1
1. Rehabilitation technology. I. Galvin, Jan C. II. Scherer, Marcia J. (Marcia Joslyn) 1948– .
[DNLM: 1. Disabled—rehabilitation. 2. Communication Aids for Disabled. 3. Self-Help Devices. WB 320 E914 1996]
RM950.E98 1996
617'.03—dc20
DNLM/DLC
for Library of Congress
96-15711
CIP

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Editorial Resources: Ruth Bloom

Library of Congress Catalog Card Number: 96-15711
ISBN: 0-8342-0664-1

Printed in the United States of America

1 2 3 4 5

Evaluating, selecting, and using appropriate assistive technology / [edited by] Jan C. Galvin, Marcia J. Scherer.
p. cm.

Includes bibliographical references and index.
ISBN 0-8342-0664-1
1. Rehabilitation technology. I. Galvin, Jan C. II. Scherer, Marcia J. (Marcia Joslyn) 1948– .
[DNLM: 1. Disabled—rehabilitation. 2. Communication Aids for Disabled. 3. Self-Help Devices. WB 320 E914 1996]
RM950.E98 1996
617'.03—dc20
DNLM/DLC
for Library of Congress
96-15711
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Editorial Resources: Ruth Bloom

Library of Congress Catalog Card Number: 96-15711
ISBN: 0-8342-0664-1

Printed in the United States of America

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